IV. General Findings from the Consumer and Provider Surveys

A. Distribution and Response

Consumer Surveys: Public Health delivered a total of 2,688 surveys to various sites throughout King County, including 65 service agencies and the offices of 34 private medical care providers and 11 private dentists. Based on follow-up inquiries, agencies and providers actually distributed approximately 1,550 surveys to consumers. The Planning Council received a total of 538 valid responses, for a return rate of 34.7%. This represents 9.6% of the estimated 5,625 persons living with HIV in the county who are presumed to be aware of their serostatus.

Distribution site codes on each survey allowed Public Health to track return rates. Table 3 shows a breakdown of survey returns by type of distribution site.

Table 3. Consumer Survey Returns by Distribution Site (N=538)

Type of Site	# Returned	% of Total
AIDS service organizations	284	53%
Medical center or hospital clinics	114	21%
Non-Western medical facilities	36	7%
Private doctor's offices	23	4%
Community health center or clinics	22	4%
AIDS residential care facilities	20	4%
Substance use recovery programs	11	2%
Other social service agencies	11	2%
Private dentist's offices	9	2%
Site code missing/removed	8	1%

Provider Surveys: Public Health delivered a total of 561 provider surveys to a wide spectrum of HIV/AIDS care providers throughout the county. These included primary care providers, case managers, mental health and substance use treatment professionals, non-Western care practitioners, private dentists and other social service providers. The Planning Council received a total of 256 valid responses, for a return rate of 46%.

The survey asked respondents to identify the nature of the specific service that they provided to persons living with HIV/AIDS. Table 4 shows a breakdown of surveys received from different types of providers.

Table 4. Provider Survey Returns by Provider Type (N=256)

Service Provided	# Returned	% of Total
Primary medical care	77	30%
Case management	32	13%
Mental health treatment/counseling	32	13%
Emotional support programs	19	7%
Housing related services	17	7%
Client advocacy services	17	7%
Substance use treatment/counseling	16	6%
Skilled nursing/hospice care	11	4%
Dental care	10	4%
Adult day health programs	9	2%
Volunteer support programs	7	3%
Alternative, non-Western therapies	6	2%
No answer	3	1%

B. Consumer Survey Demographics

In general, demographic responses on the consumer survey suggest a fairly representative sampling of persons living with HIV/AIDS (PLWH) in King County (Table 5). Survey response information was compared to PLWH demographic estimates generated by Public Health's HIV/AIDS Epidemiology Program to compare the respondents with the overall population of persons living with HIV in King County.

Although the Planning Council placed emphasis on collecting information from a wide range of persons living with HIV/AIDS, it also sought to over-sample traditionally under-served populations. These include homeless persons, PLWH with substance use histories, women, PLWH of color, youth/young adults and persons living with HIV/AIDS in South and East King County. Although the largest single response group was white MSM (60% of total), a higher proportion of persons of color, women, persons reporting heterosexual transmission, and non-Seattle King County residents responded to the survey than is represented among current King County HIV prevalence estimates.

Sex: Males accounted for 85% of the survey responses, females for 14% and transgendered persons for 1%. This represents a 14% increase in the percentage of female respondents from 1999. The overall prevalence estimates in King County are 91% male and 9% female.

Race: The survey asked respondents to check all applicable racial and ethnic categories. Response rates indicate that the survey sample was nearly identical to the racial distribution

among estimated King County PLWH. White PLWH comprised 71% of respondents, compared to 74% of estimated King County PLWH. Twelve percent of respondents identified as African-American (14% of estimated PLWH), 10% Latino/Latina (8% of estimated PLWH), 3% American Indian/Alaska Native (2% of estimated PLWH) and 2% Asian/Pacific Islander (2% estimated PLWH).

Age: Persons in the 25-29 age range are under-represented in survey responses (6% of respondents versus 13% of estimated PLWH), as are PLWH in their 30's (36% of respondents versus 47% of prevalance estimates). Conversely, persons between the ages of 40-49 are over-represented (32% versus 22%), as well as persons 50 and over (15% versus 6%). This may be due to several factors. Younger persons living with HIV are generally less likely to be aware of their serostatus than older individuals and thus would not have completed the survey. Providers of services to youth and young adults reported that younger PLWH are less likely to be actively engaged in the care system, and are also less likely to follow-up on paperwork. Despite outreach efforts, younger PLWH may not have received copies of the survey or may not have returned completed surveys.

Exposure category: The survey asked respondents to check all potential modes of transmission that they believe might have been responsible for their HIV infection. Reflective of epidemic patterns in King County, survey respondents were most likely to report HIV transmission due to male/male sexual activity (71%). Nine percent of respondents reported sharing drug needles as well as male/male sex. King County HIV prevalence estimates for these exposure categories are 70% MSM and 10% MSM/IDU.

Only 3% of respondents reported needle sharing exclusive of MSM activity, versus 7% of the King County PLWH estimates. A significantly greater percentage of survey respondents reported potential transmission risk through heterosexual contact than appears in case statistics (12% of respondents versus 5% of PLWH estimates; $p<.01$).

Annual income: No specific data exist regarding income levels of PLWH in King County against which to compare survey respondents. At least 68% of respondents are living at or below 200% of 2001 Federal Poverty Level guidelines ($17,180 per year for a single individual), which is the cut-off point for eligibility for the majority of Ryan White CARE Act funded services in King County. This figure would probably be higher if household size were factored in, but the survey did not capture this information.

Place of residence: Seventy percent of survey respondents listed Seattle zip codes as their place of residence. Six percent of respondents listed East King County zip codes and 14% listed zip codes in South King County, similar to geographic prevalence estimates of 6% and 13%, respectively. This represents an 18% increase in the percentage of non-Seattle survey respondents from the 1999 needs assessment process.

HIV health status: Efforts to sample consumers across the spectrum of HIV disease appear to be successful. Thirty percent of respondents self-reported as being HIV+ without symptoms (representing a 25% increase in the percentage of HIV+ asymptomatic survey respondents from

1999), with an additional 16% identifying as being HIV+ and symptomatic. Twenty-seven percent of respondents stated that they had received an AIDS diagnosis based on low T-cell counts, with the remaining 26% reporting being AIDS diagnosed with an opportunistic infection.

Other demographic indicators:

- Eight percent of respondents reported having dependent children.
- Thirty percent of respondents reported having been diagnosed with a mental illness. (The survey did not ask the specific nature of the mental illness diagnosis.)
- Eleven percent reported being currently homeless or without a permanent place of residence within the past year.
- Seven percent reported being in jail or prison in the past year.
- Five percent reported using needles to inject street drugs in the past year.
- Fifteen percent reported using non-injectible street drugs in the past year.

Table 5. Demographic Comparison of 2001 Consumer Survey Respondents and King County PLWH Estimates (as of 4/01)

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=538)		KC PLWH ESTIMATES (N=7,500)
SEX			
Male	456	(85%)	(91%)
Female	75	(14%)	(9%)
Transgendered (M-to-F)	6	(1%)	N/A
Transgendered (F-to-M)	0	(0%)	N/A
No response	0	(0%)	N/A
RACE*			
African-American	62	(12%)	(14%)
American Indian/Alaska Native	14	(3%)	(2%)
Asian/Pacific Islander	13	(2%)	(2%)
Caucasian	380	(71%)	(74%)
Latino/Latina	52	(10%)	(8%)
Other	2	(<1%)	(<1%)
No response	12	(2%)	N/A
AGE			
<13	1	(<1%)	(<1%)
13-24	19	(4%)	(11%)
25-29	31	(6%)	(13%)
30-39	191	(36%)	(47%)
40-49	174	(32%)	(22%)
50 and over	82	(15%)	(6%)
No response	40	(7%)	N/A
EXPOSURE CATEGORY*			
Male/male sex (non-IDU)	382	(71%)	(70%)
Injection drug use (non-MSM)	16	(3%)	(7%)
IDU and male/male sex	49	(9%)	(10%)
Heterosexual contact	62	(12%)	(5%)
Transfusion/blood products	24	(4%)	(1%)
Parent at risk/has HIV	2	(<1%)	(<1%)
Other/unknown	49	(8%)	(7%)
No response	9	(2%)	N/A

*Respondents were asked to check all applicable answers. Totals are greater than 100%.

Table 5 (Continued)

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=538)		KC PLWH ESTIMATES (N=7,500)
ANNUAL INCOME			
Less than $8,500	211	(39%)	N/A
$8,501-$17,000	155	(29%)	N/A
$17,001-$25,000	59	(11%)	N/A
$25,001-$30,000	33	(6%)	N/A
$30,001-$40,000	24	(5%)	N/A
Over $40,000	45	(8%)	N/A
No response	11	(2%)	N/A
PLACE OF RESIDENCE			
Seattle	378	(70%)	(81%)
East King County	33	(6%)	(6%)
South King County	74	(14%)	(13%)
No response	53	(10%)	N/A
HIV STATUS			
HIV+, without symptoms	160	(30%)	HIV+: 67%
HIV+, with symptoms	85	(16%)	
AIDS diagnosed, by T-cell count	147	(27%)	AIDS dx: 33%
AIDS diagnosed, by OI	141	(26%)	
No response	5	(1%)	
OTHER DEMOGRAPHIC CHARACTERISTICS			
Have dependent children	42	(8%)	N/A
Ever diagnosed with mental illness	162	(30%)	N/A
In past year:			
Homeless	58	(11%)	N/A
In jail or prison	35	(7%)	N/A
Used needles to inject drugs	44	(8%)	N/A
Used other street drugs	81	(15%)	N/A

C. Provider Survey Demographics

The survey asked providers about the total number of clients with HIV/AIDS on their active caseload and asked them to characterize their HIV/AIDS clientele by several demographic indicators. Averaging valid responses from all returned surveys derived percentages for each of the demographic characteristics. Based on response to these demographic questions, it appears that the client population served by providers survey respondents is fairly representative of PLWH in King County (Table 6). Efforts to over-sample among providers of services to women, persons of color and non-MSM proved successful based on demographic frequencies.

Total caseload: The average caseload reported by providers is 51 clients, with a range of one to 600. Primary medical care providers (n=77) reported average caseloads of 55 clients, with a range of two to 350 and a median of 27 clients. Case managers (n=32) reported an average caseload of 50 clients, with a range of two to 134 and a median caseload of 42 clients.

Sex: The average client caseload among responding providers was 82% male, 18% female and 1% transgendered. HIV prevalence estimates in King County are 91% male and 9% female.

Race: The racial breakdown of the average provider caseload was 71% white and 26% persons of color, as compared to King County PLWH estimates of 74% and 26%, respectively. Within non-white categories, provider caseload percentages and King County estimates were relatively similar, with providers reporting that 15% of their client were African-American (KC estimate: 14%), 8% Latino/Latina (KC estimate: 8%), 2% American Indian/Alaska Native (KC estimate 2%) and 1% Asian/Pacific Islander (KC estimate: 2%).

Age: Unlike consumer survey percentages, provider caseloads were more likely to over-represent young adult clients and somewhat less likely to represent PLWH between the ages of 25-39. Less than one percent of clients served were under the age of 13, similar to King County PLWH estimates. Twelve percent of provider caseloads were between the ages of 13-24, similar to County estimates of 11%. Eighteen percent of clients were between 20-29 years of age (KC estimate: 13%), 42% between 30-39 (KC estimate: 45%) and 28% over 40 years of age (KC estimate: 28%).

Exposure category: The survey asked providers to classify their clients by primary modes of HIV exposure. Providers reported that 63% of their clients were exposed through male/male sex, with an additional 9% of clients dually exposed through MSM contact and injection drug use. King County PLWH estimates for these populations are 70% and 10%, respectively. Providers reported that 15% of their clients were primarily exposed through injection drug use (KC estimate: 7%). Similar to the consumer survey, providers reported higher percentages of clients exposed through heterosexual contact (11%) than are represented in King County PLWH estimates (5%).

Annual income: Providers reported that an average of 80% of their clients are living at or below 200% of Federal Poverty Level, with 51% earning less than 100% of FPL. As with the consumer survey, this figure would actually be higher if household size were factored in, but the survey did

not capture this information.

Place of residence: Providers reported seeing clients whose distribution throughout the county was fairly similar to King County PLWH estimates. Seventy-seven percent of clients are from Seattle (KC estimate: 81%), 6% from East King County (KC estimate: 6%) and 10% from South King County (KC estimate: 13%). The remaining 6% of clients served reside outside King County, but receive service from King County-based providers.

Primary language: Providers reported that 94% of their clients are primarily English speaking, with 5% identifying Spanish as their primary language. This represents almost a twofold increase from the 1999 survey in the percentage of Spanish-speaking clients. Seventeen percent of all responding providers noted that at least one of their clients spoke a primary language other than English or Spanish, representing 1% of all consumers served. The most frequently spoken languages for these consumers are Amharic (and other African languages) and a variety of Southeast Asian languages.

Other demographic indicators: On average, providers reported higher percentages of other medical or social co-morbidities than in 1999. In 2001, providers reported that:

- Forty-seven percent of their clients have been diagnosed with a mental illness (up from 32% from 1999 provider reports)
- Forty-six percent have a history of chemical dependency (up from 40% in 1999)
- Fifteen percent are currently homeless or have been without a permanent place of residence within the past year (up from 10% in 1999)
- Eleven percent have been in jail or prison in the past year (up from 8% in 1999).

Table 6. Demographic Comparison of 1999 Provider Survey Client Demographics and King County PLWH Estimates (as of 4/01)

Characteristics	Client Demographics From Provider Surveys (N=256)	KC PLWH Estimates (N=7,500)
Average client caseload = 51		
SEX		
Male	82%	91%
Female	18%	9%
Transgendered (M-to-F)	<1%	N/A
Transgendered (F-to-M)	<1%	N/A
RACE		
African-American	15%	14%
American Indian/Alaska Native	2%	2%
Asian/Pacific Islander	1%	2%
Caucasian	71%	74%
Latino/Latina	8%	8%
Other	2%	N/A
AGE		
<13	<1%	<1%
13-24	12%	11%
20-29	18%	13%
30-39	42%	47%
40 and over	28%	28%
EXPOSURE CATEGORY		
Male/male sex	63%	70%
Injection drug use (non-MSM)	15%	7%
IDU and male/male sex	9%	10%
Heterosexual contact (non-IDU)	11%	5%
Transfusion/blood products	1%	1%
Parent at risk/has HIV	<1%	<1%
Other	<1%	6%
ANNUAL INCOME		
Under 100% of FPL	51%	N/A
101-200% of FPL	29%	N/A
201-300% of FPL	12%	N/A
Over 300% of FPL	8%	N/A

Table 6 (Continued)

Characteristics	Client Demographics From Provider Surveys (N=256)	KC PLWH Estimates (N=7,500)
PLACE OF RESIDENCE		
Seattle	77%	81%
East King County	6%	6%
South King County	10%	13%
Outside King County	6%	N/A
PRIMARY LANGUAGE		
English	94%	N/A
Spanish	5%	N/A
Other	1%	N/A
OTHER DEMOGRAPHIC CHARACTERISTICS		
Homeless (in past year.)	15%	N/A
In jail or prison (in past year)	11%	N/A
Hx. of chemical dependency	46%	N/A
Diagnosed w/mental illness	47%	N/A

D. Medical Care Access

Ninety-three percent of survey respondents reported current use of ambulatory medical care. This figure is identical to the response from the 1999 surveys. Only 1% of survey respondents (6 out of 538) reported that they needed, but could not medical care.

An additional 5% of respondents (n=24) identified outpatient medical care as a service that they did not need. Of these 24 individuals, one-third reported that their viral loads were undetectable and almost three-quarters reported currently taking protease inhibitors and/or antiviral medications. This suggests that these consumers have had at least some contact with medical professionals regarding their HIV disease, although they may not consider themselves to be currently using the service.

Women were somewhat less likely than men to report utilization of primary medical care during the past year (89% versus 93%), although this finding is not statistically significant. No other statistically significant differences emerged regarding utilization of medical care based on other demographic factors.

Seventy-nine percent of consumers reported currently taking some form of antiviral medications. (Table 7) This represents a statistically significant increase from 69% of consumers who reported taking antiviral medications on the 1999 survey. However, the percent of consumers who report taking protease inhibitors and other drugs to treat or prevent opportunistic infections has

decreased significantly in the past two years. Based on input from consumers in focus groups and key informant interviews with providers, it appears that the decrease in the percentage of PLWH on protease inhibitors is related to clients choosing to no longer take these medications after having been taking them for several years, as well as clients deciding to discontinue medications due to negative side effects.

Table 7: Current Medication Status

CONSUMERS CURRENTLY TAKING HIV-RELATED MEDICATIONS:			
	2001 (N=538)		1999
On antiviral medications	423	79%	69%
On protease inhibitors	285	53%	60%
On other drugs to treat/prevent OI	229	43%	51%

E. Service Utilization

Overall service utilization: The consumer survey inquired about 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they needed and used, did not need, or needed but could not get. Utilization rates were calculated based on services which consumers checked as "need and use."

In order to make the data more useful in making funding decisions, responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting. This was necessary because several Ryan White service categories include component services (e.g., the Ryan White category of "Counseling (Emotional Support)" includes one-on-one peer support, support groups and spiritual and religious counseling). (See Appendix G for a breakdown of the specific services associated with each Ryan White eligible service category.) Cumulative responses by service category are reported in Table 8.

As in previous years, utilization of most services increased with the person's level of illness. In particular, consumers who were AIDS diagnosed used programs that provide assistance with activities of daily living at higher rates than asymptomatic PLWH. These include food and meal programs (56% versus 33%), volunteer home chore services (17% versus 7%) and transportation services (37% versus 25%). Persons with AIDS diagnoses were also significantly more likely than asymptomatic consumers to use case management (86% versus 68%), peer counseling (62% versus 46%), housing assistance (51% versus 33%) and emergency financial assistance (48% versus 32%). Utilization rates for ambulatory medical care and prescription drug programs were similar among the two groups. In general, PLWH who were HIV+ and symptomatic displayed utilization rates somewhere between the other two groups.

Table 8. Service Utilization from Consumer Surveys (N=538)

Rank	Service	Responses	%
1	Ambulatory/outpatient medical care	499	93%
2	Client advocacy	448	83%
3	Case management	425	79%
4	Dental care	383	71%
5	Insurance programs	307	57%
6	Counseling (emotional support)	302	56%
7	Drug prescription program (ADAP)	285	53%
8	Mental health therapy/counseling	261	49%
9	Food/meals	256	48%
10	Referral	250	46%
11	Housing assistance/related services	238	44%
12	Direct emergency financial assistance	222	41%
13	Alternative, non-Western therapies	211	39%
14	Transportation	178	33%
15	Legal assistance	174	32%
16	Treatment adherence support	161	30%
17	Health education/risk reduction	99	18%
18	Home health care	97	18%
19	Substance use treatment/counseling	86	16%
20	Adult day health	85	16%
21	Volunteer home chore	66	12%
22	Child care	16	3%

Additional Utilization Data by Categories:

Alternative/non-Western therapies: Almost all of the consumers who are currently using alternative therapies are also receiving Western medical care (204 out of 211; 97%). Consumers who reported using alternative therapies were also asked if they considered it to be their primary form of medical care. Of those using alternative therapies, 15% (32 out of 211) stated that they consider non-Western therapies as their primary source of medical care.

Client Advocacy: A high percentage of consumers reported using one or more of the various

components of client advocacy (88%). Within the client advocacy category, the component service that was most frequently used by consumers was medical information about HIV/AIDS (used by 74% of respondents). Thirty-three percent of respondents reported using non-case management peer advocacy services, 30% reported using benefits counseling and 7% of respondents reported currently using interpreter services.

Counseling (emotional support): Among the component services included in this category, consumers reported highest utilization of support groups (used by 41% of respondents) and one-on-one peer support (33%). Twenty-six percent of respondents reported using spiritual and religious counseling.

Direct emergency financial assistance: Among the component services included in this category, approximately equal numbers of consumers reported receiving help paying for groceries (32%) and help paying for utilities (31%). .

Food/meals: Among the component services included in this category, twice as many consumers reported using food bank/free groceries services (42%) as reported receiving home-delivered meals (21%).

Comparison Between 1999 and 2001 Service Utilization: Utilization rates remained fairly constant in approximately two-thirds of service categories between 1999 and 2001. The percentage of consumers who reported using each service remained virtually unchanged in 9 of the 20 comparable service categories (an increase or decrease of 3 percentage points or less). (Table 9).

Utilization of several types of services increased from 1999 to 2001. These included case management, insurance programs, transportation and mental health therapy:

- The increase in consumers who reported using case management and transportation may be due to demographic changes, both within the overall population of PLWH and among survey respondents. Utilization of case management tends to be higher among persons of color and injection drug using PLWH, two populations that increased in the overall AIDS case figures and among survey respondents.

- The increase in PLWH who are using insurance programs is offset by a slight decrease in those who reported using the Washington State AIDS drug assistance program (ADAP). This may signal that consumers are enrolling in programs that offer comprehensive medical and prescription drug benefits, and are somewhat less dependent on ADAP to primarily cover the costs of their medications.

Table 9. Comparison Between 1999 and 2001 Service Utilization

Service	1999 % (N=509)	2001 % (N=538)
Adult day health	11%	16%
Alternative/non-Western therapies	36%	39%
Ambulatory/outpatient medical care	92%	93%
Case management	72%	79%
Child care	2%	3%
Client advocacy	82%	83%
Counseling (emotional support)	57%	56%
Dental care	70%	71%
Direct emergency financial assistance	46%	41%
Drug prescription programs (ADAP)	57%	53%
Food/meals	51%	48%
Home health care	18%	18%
Housing assistance/related services	42%	44%
Insurance programs	50%	57%
Legal assistance	37%	32%
Mental health therapy/counseling	43%	49%
Referral	52%	46%
Substance use treatment/counseling	13%	16%
Transportation	26%	33%
Volunteer home chore	15%	12%

- A somewhat higher percentage of 2001 survey respondents reported having been diagnosed with a mental illness than in 1999 (30% versus 26%). In addition, providers reported much higher percentages of their caseloads being diagnosed with mental illness (47% in 2001 versus 32% in 1999). These figures, coupled with increased availability of Ryan White-funded mental health services, may explain the increased utilization of these services.

No service category demonstrated a significant decrease in utilization during the past two years, although use of telephone referrals to dental and medical care and legal assistance decreased somewhat. Tighter eligibility criteria for direct emergency financial assistance also seem to have resulted in somewhat lower consumer utilization of this service.

F. Service Priorities

Consumer-identified priorities: The consumer survey included a one-page list of the 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. The survey asked consumers to identify up to seven services that they considered as most important to them. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories shown below, and ranked by overall percentage of response. Table 10 includes cumulative responses of service priorities (services which consumers rated as one of their seven most important services).

Consumers ranked ambulatory medical care as the highest service priority, with almost two-thirds of respondents stating that it was a priority for them. Medical care was followed by dental care, case management, housing assistance, insurance programs and drug prescription programs as the top service priorities.

The percentage difference between each of the top three service priorities (ambulatory medical care, dental care and case management) are all statistically significant, as are the difference between the services ranked fourth and fifth (housing and insurance programs). While these differences suggest a clear demarcation in consumer priority rankings, the services ranked eighth through twelfth are relatively equal in the percentage of consumers identifying them as service priorities.

Level of illness (HIV+ asymptomatic, HIV+ with symptoms or AIDS diagnosed) appears to have relatively little impact on the ways in which consumers prioritized most services. This applies both to the actual rank order of the services, as well as to the relative importance of the service based on the percentage of those who reported it as a priority.

Consumers with AIDS diagnoses were generally more likely than asymptomatic respondents to prioritize assistance with activities of daily living (food and meals: 33% versus 18%; transportation: 18% versus 8%; volunteer home chore: 10% versus 4%; and home health care: 12% versus 6%). Persons with AIDS diagnoses were also more likely to prioritize case management (53%) than either HIV+, asymptomatic persons (41%) or HIV+ respondents with symptoms (42%).

Dental care was the sole service that was significantly more likely to be prioritized by HIV+ asymptomatic consumers. Dental care was ranked as a service priority by 66% of these individuals, versus 42% of HIV+ persons with symptoms and 48% of those with AIDS diagnoses.

Table 10. Service Priorities from Consumer Surveys (N=511; 27 missing/invalid responses)

Rank	Service	Total Votes	%
1	Ambulatory/outpatient medical care	324	63%
2	Dental care	284	56%
3	Case management	256	50%
4	Housing assistance/related services	241	47%
5	Insurance programs	209	41%
6	Drug prescription program (ADAP)	202	40%
7	Client advocacy	181	35%
8	Direct emergency financial assistance	156	31%
9	Alternative, non-Western therapies	147	29%
10 (tie)	Food/meals	146	29%
10 (tie)	Mental health therapy/counseling	146	29%
12	Counseling (emotional support)	141	28%
13	Legal assistance	80	16%
14	Transportation	72	14%
15	Adult day health	52	10%
16	Referral	50	10%
17	Home health care	48	9%
18	Substance use treatment/counseling	45	9%
19	Volunteer home chore	39	8%
20	Treatment adherence support	29	6%
21	Health education/risk reduction	21	4%
22	Child care	11	2%

Comparison between 1999 and 2001 consumer service priorities: Relative service priority rankings changed little between 1999 and 2001 (Table 11). Only three of the twenty comparable service categories moved three or more places up or down in overall consumer priority rankings over the past two years. (Health education/risk reduction and treatment adherence support were not included on the 1999 consumer survey.)

Table 11. Comparison Between 1999 and 2001 Consumer-Identified Service Priorities

Service	1999 (N=503)		2001 (N=511)	
	Rank	%	Rank	%
Adult day health	17 (tie)	9%	15	10%
Alternative/non-Western therapies	10	28%	9	29%
Ambulatory/outpatient medical care	3	55%	1	63%
Case management	4	51%	3	50%
Child care	20	2%	22	2%
Client advocacy	7	35%	7	35%
Counseling (emotional support)	11	27%	12	28%
Dental care	2	55%	2	56%
Direct emergency financial assistance	9	34%	8	31%
Drug prescription programs (ADAP)	1	62%	6	40%
Food/meals	6	35%	10 (tie)	29%
Home health care	15 (tie)	10%	17	9%
Housing assistance/related services	5	47%	4	47%
Insurance programs	8	34%	5	41%
Legal assistance	13	21%	13	16%
Mental health therapy/counseling	12	23%	10 (tie)	29%
Referral	15 (tie)	10%	16	10%
Substance use treatment/counseling	19	7%	18	9%
Transportation	14	13%	14	14%
Volunteer home chore	17 (tie)	9%	19	8%

NOTE: The categories of "Health Education/Risk Reduction" (ranked 21st in 2001) and "Treatment Adherence Support" (ranked 20th in 2001) were not included on the 1999 consumer survey. As a result, cross-year comparisons are not possible.

Drug prescription programs, ranked as the top consumer priority in 1999, dropped to the sixth highest priority (ranked as a priority by 62% of consumers in 1999 and 40% in 2001). Conversely, consumers were more likely in 2001 to prioritize insurance programs, which moved up from eighth to fifth in the priority rankings (1999: 34%; 2001: 41%). Based on information from consumer focus group participants and providers of services, it appears that reasons for these changes are two-fold: the continuing decline in private insurance options in Washington State and growing awareness of the need to ensure comprehensive medical coverage for PLWH, not just prescription drug access.

Food and meal programs dropped from the sixth highest priority in 1999 (35% listing the service as a priority) to a tie for tenth in 2001 (29%). This may be a result of the increased percentage of HIV+ asymptomatic respondents to the survey, many of whom are less dependent than disabled consumers on having this service provided.

In addition to the aforementioned services, three other categories experienced significant changes in the overall percentage of consumers who listed them as priorities between the two survey years. These included ambulatory medical care, legal assistance and mental health therapy/counseling. Sixty-three percent of respondents prioritized ambulatory care in 2001, up from 55% in 1999. The percent of consumers who prioritized mental health therapy also increased, from 23% in 1999 to 29% in 2001. Legal assistance was significantly less likely to be listed as a priority, dropping from 21% of respondents in 1999 to 16% in 2001.

Provider-identified service priorities: The provider survey included the same one-page list of 36 types of HIV/AIDS-related services as was included in the consumer version. The survey asked each responding provider to identify up to seven services that they considered as most important for the clients they served. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 12 reports cumulative responses of provider priorities. (In order to insure that provider-identified priorities were not biased by over-sampling certain types of providers (i.e., medical providers and case managers), additional data runs were conducted controlling for provider type. Analysis revealed that provider type did not significantly skew identification of priorities or gaps.)

Providers ranked ambulatory care as the highest service priority for their clients, followed by case management, mental health therapy/counseling, drug prescription programs, and substance use treatment/counseling.

Table 12. Service Priorities from Provider Surveys (N=251; 5 missing/invalid responses)

Rank	Service	Total Votes	%
1	Ambulatory/outpatient medical care	191	76%
2	Case management	170	68%
3	Mental health therapy/counseling	158	63%
4	Drug prescription program (ADAP)	137	55%
5	Substance use treatment/counseling	123	49%
6	Housing assistance/related services	103	41%
7	Client advocacy	98	39%
8	Treatment adherence support	68	27%
9	Counseling (emotional support)	63	25%
10	Insurance programs	57	23%
11 (tie)	Transportation	54	22%
11 (tie)	Dental care	54	22%
13	Adult day health	45	18%
14	Home health care	40	16%
15	Food/meals	29	12%
16 (tie)	Alternative, non-Western therapies	25	10%
16 (tie)	Health education/risk reduction	25	10%
18	Direct emergency financial assistance	24	10%
19	Legal assistance	22	9%
20	Volunteer home chore	13	5%
21 (tie)	Child care	4	2%
21 (tie)	Referral	4	2%

Comparison between 1999 and 2001 provider-identified service priorities: Relative service priority rankings changed little between 1999 and 2001 (Table 13). Similar to the consumer surveys, only three of the twenty comparable service categories moved three or more places up or down in priority rankings over the past two years, and none of these were among the top nine services prioritized by providers. (Health education/risk reduction and treatment adherence support were not included on the 1999 provider survey.)

Table 13. Comparison Between 1999 and 2001 Provider-Identified Service Priorities

Service	1999 (N=216)		2001 (N=251)	
	Rank	%	Rank	%
Adult day health	13	18%	13	18%
Alternative/non-Western therapies	16	13%	15	10%
Ambulatory/outpatient medical care	3	69%	1	76%
Case management	1	72%	2	68%
Child care	19	3%	21 (tie)	2%
Client advocacy	6	46%	7	39%
Counseling (emotional support)	8	32%	9	25%
Dental care	9	29%	11 (tie)	22%
Direct emergency financial assistance	10	26%	18	10%
Drug prescription programs (ADAP)	2	70%	4	55%
Food/meals	11	19%	16	12%
Home health care	15	14%	14	16%
Housing assistance/related services	7	38%	6	41%
Insurance programs	14	16%	10	23%
Mental health therapy/counseling	5	53%	3	63%
Substance use treatment/counseling	4	57%	5	49%
Transportation	12	19%	11 (tie)	22%
Volunteer home chore	18	4%	20	5%

NOTE: The categories of "Health Education/Risk Reduction" (ranked 21st in 2001) and "Treatment Adherence Support" (ranked 20th in 2001) were not included on the 1999 provider survey. As a result, cross-year comparisons are not possible.

Insurance programs demonstrated the greatest upward movement in ranking, rising from fourteenth highest priority (16% of providers listing this service as a priority in 1999) to tenth in 2001 (23%). Two services dropped significantly in the rankings during the past two years: direct emergency financial assistance dropped from tenth priority (26%) to eighteenth (10%) and food/meals fell from eleventh (19%) to sixteenth (12%).

In addition to the aforementioned services, two other categories experienced significant changes in the overall percentage of providers who listed them as priorities. These included drug prescription programs (noted as a priority by 70% of providers in 1999 and 55% in 2001) and mental health therapy/counseling (53% in 1999; 63% in 2001). Providers seem to concur with

consumers regarding the increasing priority of comprehensive insurance coverage, as well as continuing to support coverage of state-administered drug programs. Providers noted that increasing percentages of their caseloads are persons with diagnoses of mental illness, leading to an increase in the percentage of providers who prioritized mental health treatment for their clients.

Comparison between 2001 consumer and provider service priorities: Comparisons between consumer and provider responses yield numerous differences in both priority rankings and percentages. Statistically significant differences emerged in almost two-thirds of all services under consideration. In general, providers were more likely to prioritize clinical services, while consumers were more likely to prioritize ancillary services, particularly those that provide financial and in-home support.

Significant disparities are visible even in those service categories that both consumers and providers rank among their top priorities. Although both groups assign high priority to primary medical care (ranked first by both consumers and providers), case management (consumer rank: 3; provider rank: 2) and housing services (consumer rank: 4; provider rank: 6), the relative importance placed on these services is quite different. The disparity is greatest in the area of case management, with 68% of providers ranking it as a service priority, versus 50% of consumers. Significant differences are also present in the percent prioritizing outpatient medical care (76% of providers versus 63% of consumers).

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify substance use treatment and mental health counseling as service priorities. This trend continues in 2001, with even greater disparity between the two groups. Providers were over five times more likely than consumers to prioritize substance use treatment (49% versus 9%) and over twice as likely to prioritize mental health counseling (63% versus 29%). These discrepancies were also noted by providers during the key informant interview process, many of whom reported increases in the incidence of dual and triple diagnoses (HIV/mental illness/chemical dependency) among their client populations, coupled with consumer resistance to and/or lack of access to these services.

Providers were also significantly more likely to prioritize the new category of treatment adherence support for their clients (27% versus 6%). As noted in key informant interviews, providers stated that mental illness and substance use often pose the greatest barriers to consumers' ability to maintain their treatment regimens. Thus, consumers who refuse mental health and/or substance use treatment may also not recognize treatment adherence support as an important component of their medical care.

Consumers were significantly more likely than providers to assign priority to alternative/non-Western therapies (29% versus 10%), dental care (56% versus 22%), direct emergency financial assistance (31% versus 10%), and food and meal programs (29% versus 12%). Previous needs assessments revealed similar disparities, and the percentage difference between consumer and provider perceptions of these services has not lessened.

Continuing a trend first noted in 1999, a significant disparity exists between consumer and provider prioritization of insurance programs, with consumers being significantly more likely to prioritize the service (34% versus 16%; p<.01). This may be due to gathering responses from a diverse group of provider types. Provider survey respondents who are not in a clinical or case management setting may be unaware of the ways in which their particular clients pay for medical care and may not see insurance as a priority when related to the specific service they provide.

G. Service Gaps

Consumer-identified service gaps: As previously stated, consumers identified each of the 36 services offered in the King County Continuum of Care as ones that they needed and used, did not need, or needed but could not get. Each service that a consumer identified as "needed, but could not get" is considered a service gap. These responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Cumulative categorical service gap responses appear in Table 14.

As shown in the table, consumers identified very few of the services available in the Seattle-King County Continuum of Care as being grossly deficient. Several differences emerged, however, when comparing responses among specific sub-populations. (These will be discussed in the population-specific information found in Section V.)

Consumers considered lack of emergency financial assistance as the number one service gap. Almost one quarter of survey respondents noted this gap. Among the sub-components of this service category, 19% of respondents identified a gap in assistance with utility bills and 18% identified a gap in help paying for groceries. These results are not surprising, given the very low income levels reported by a large percentage of the survey population. Providers noted that, for many of their clients, financial problems such as these pre-date the clients' HIV diagnosis and are further complicated by the onset of disease.

Twenty-two percent of survey respondents noted a gap in the provision of alternative, non-Western therapies. Among the component parts of this category, 18% noted a gap in access to naturopathy and herbal medicine and 14% noted a gap in acupuncture/Chinese medicine services. Based on information from service providers and consumers in focus groups, PLWH continue using these services to alleviate pain and other physical symptoms, and lessen the side effects of HIV-related medications. Service gaps exist for consumers who are not able to afford the services (due to lack of insurance coverage for non-Western medical services or having incomes above Ryan White eligibility levels) or because the services are not geographically accessible.

Table 14. Service Gaps from Client Surveys (N=538)

Rank	Service	Total Votes	%
1	Direct emergency financial assistance	130	24%
2	Alternative, non-Western therapies	121	22%
3	Counseling (emotional support)	107	20%

4	Client advocacy	105	20%
5	Housing assistance/related services	103	19%
6	Dental care	81	15%
7	Legal assistance	57	11%
8	Mental health therapy/counseling	56	10%
9	Food/meals	54	10%
10	Referral	49	9%
11	Volunteer home chore	36	7%
12	Insurance programs	33	6%
13 (tie)	Adult day health	27	5%
13 (tie)	Home health care	27	5%
15	Treatment adherence support	26	5%
16	Drug prescription program	25	5%
17	Case management	24	4%
18	Substance use treatment/counseling	20	4%
19	Transportation	18	3%
20	Health education/risk reduction	14	3%
21 (tie)	Ambulatory/outpatient medical care	6	1%
21 (tie)	Child care	6	1%

Other top five ranked service gaps include counseling (peer emotional support), client advocacy and housing assistance. Within the counseling (emotional support) category, one-to-one peer support was the largest gap (identified as a gap by 14% of consumers), followed by support groups (12%) and spiritual and religious counseling (7%). Within the client advocacy category, the greatest gaps were reported in the areas of benefits counseling (other than by a case manager) (11%) and peer or client advocacy (10%). Only 5% of respondents identified gaps in accessing medical information about HIV/AIDS, while 1% of respondents identified a gap in accessing interpreter services. As regards the components of housing assistance, 14% of consumers reported difficulty in getting help paying rent and 13% reported a gap in help finding low income housing.

As in 1999, few significant differences emerged in service gap identification based on level of illness. In 1997, persons who were HIV+ and symptomatic were almost twice as likely as other consumers to identify gaps in service provision in almost all categories. This year, HIV+, symptomatic consumers were no more likely than either HIV+ asymptomatic or AIDS-diagnosed persons to note gaps in services.

The sole category in which a statistically significant distinction based on level of illness was housing related services. Twenty-nine of HIV+ asymptomatic respondents identified at least one of the components of housing assistance as a service they needed, but could not get, as opposed to 20% of HIV+ symptomatic and 14% of persons with AIDS diagnoses. Based on guidance from the HIV/AIDS Housing Committee, AIDS-defining disability remains one of the eligibility criteria for placement in permanent and transitional AIDS housing. This is due largely to resource limitations in the number of units available within the HIV system, and a critical housing issue in King County in general. As a result, consumers who are not disabled by their HIV, while they are eligible for rental assistance and placement in emergency shelter, may be more likely to identify a gap in their access to permanent and transitional housing.

Comparison between 1999 and 2001 consumer-identified service gaps: Very few significant changes emerged between consumer-identified service gaps from 1999 to 2001 (Table 15). Based on input from participants in focus groups, it appears that this is due to several factors, depending on the service category. In some instances, this may suggest an insurmountable, ongoing gap, such as with financial assistance, in which Ryan White funds are incapable of fulfilling consumer need. In others, such as counseling/emotional support, it may suggest that a prior gap has been filled, but a new gap has developed in an emerging consumer sub-population such as the one identified in 2001 by Latino men.

The sole significant increase in identified gaps occurred in the category of client advocacy. The service ranked as the 10th highest gap in 1999, with 8% of consumers identifying lack of access to one or more of the sub-components of this category (benefits counseling other than by a case manager, medical information about HIV/AIDS, interpreter services and peer or client advocacy). In 2001, client advocacy rose to the number four gap, with 20% of consumers identifying a service gap in this category. A growing gap in benefits counseling accounts for this increase, particularly as more low income and non-resident consumers are accessing services.

Although housing remains among the top five service gaps identified by consumers, the percentage of consumers who identified access gaps in housing assistance and related services decreased from 24% in 1999 to 19% in 2001. This may be due to Planning Council decisions about increasing the pool of emergency rental assistance funds available to consumers, since the percentage of consumers who reported current homelessness during the past two survey periods has not increased significantly.

Table 15. Comparison Between 1999 and 2001 Consumer-Identified Service Gaps

Service	1999 % (N=509)	2001 % (N=538)
Adult day health	6%	5%
Alternative/non-Western therapies	25%	22%
Ambulatory/outpatient medical care	1%	1%

Case management	5%	4%
Child care	2%	1%
Client advocacy	8%	20%
Counseling (emotional support)	19%	20%
Dental care	17%	15%
Direct emergency financial assistance	24%	24%
Drug prescription programs (ADAP)	6%	5%
Food/meals	12%	10%
Home health care	5%	5%
Housing assistance/related services	24%	19%
Insurance programs	9%	6%
Legal assistance	11%	11%
Mental health therapy/counseling	13%	10%
Referral	7%	9%
Substance use treatment/counseling	2%	4%
Transportation	7%	3%
Volunteer home chore	8%	7%

NOTE: The categories of "Health Education/Risk Reduction" (reported as a gap by 3% of consumers in 2001) and "Treatment Adherence Support" (reported as a gap by 5% of consumers in 2001) were not included on the 1999 consumer survey. As a result, cross-year comparisons are not possible.

Provider-identified service gaps: The provider survey asked respondents to identify service gaps for the clients they served using the same list of HIV/AIDS-related services from which priorities were identified. Each responding provider was asked to check any of the services which a substantial number of their clients needed, but had difficulty in accessing. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 16 includes cumulative responses of provider-identified service gaps.

Table 16. Service Gaps from Provider Surveys (N=253)

Rank	Service	Total Votes	%
1	Housing assistance/related services	112	44%
2	Substance use treatment/counseling	81	32%
3	Mental health therapy/counseling	77	30%
4	Client advocacy	71	28%

5	Dental care	69	27%
6	Counseling (emotional support)	63	25%
7	Transportation	58	23%
8	Treatment adherence support	53	21%
9	Direct emergency financial assistance	45	18%
10	Insurance programs	44	17%
11	Home health care	36	14%
12	Alternative, non-Western therapies	35	14%
13	Legal assistance	34	13%
14	Drug prescription program	32	13%
15	Adult day health	31	12%
16	Case management	28	11%
17	Ambulatory/outpatient medical care	26	10%
18	Food/meals	25	10%
19	Volunteer home chore	23	9%
20	Child care	16	6%
21	Health education/risk reduction	14	6%
22	Referral	8	3%

Higher percentages of providers identified gaps in services than did consumers due to the fact that providers were asked to consider a service as a gap if a substantial number of their clients had trouble accessing a service, while each consumer vote represents the response of a single individual. As a result, provider-identified service gaps are useful as a measure of provider opinions about the Continuum of Care, rather than in determining the possible magnitude of service gaps for the population of PLWH in King County.

As in 1999, providers identified housing assistance and housing related services as the number one gap for the clients they served. In key informant interviews, providers pointed to long waiting lists for subsidized housing, limited options for PLWH with families and dependent children, rising rental costs and low vacancy rates as key barriers. Many providers noted that locating housing for their clients who are actively substance using and/or have criminal histories can be extremely difficult.

Providers also ranked substance use treatment and mental health counseling among the top service gaps for their HIV+ clients. This is consistent with provider reports that growing percentages of their caseloads are presenting with significant mental health issues (ranging from

situational depression to psychoses) and substance use histories (with increasing numbers of clients with multi-drug use). Although many providers noted that communication and collaboration between the HIV, mental health and substance use systems has improved in recent years, they also noted that many barriers still exist in helping their clients access these services. Among the most common barriers noted were client disinterest in using the services, denial that the service was necessary, and lack of insurance coverage and payment options.

It is also interesting to note that more providers reported gaps in helping their clients access abstinence-based substance use treatment programs than harm reduction programs. Twenty-nine percent of providers reported a gap in programs that help clients quit drug or alcohol use versus 17% who reported a gap in programs that help clients manage their use. It is unclear whether this points to improved access in recent years to harm reduction programs, or a feeling on the part of some providers that abstinence from substance use is the appropriate treatment modality for their clients.

Within the client advocacy category, the greatest gaps were reported in the areas of benefits counseling (other than by a case manager) (10%) and medical information about HIV/AIDS (9%). Seven percent of respondents identified gaps in accessing interpreter services, and 6% identified a gap in peer advocacy.

Comparison between 1999 and 2001 provider-identified service gaps: Very few significant changes emerged between provider-identified service gaps from 1999 to 2001 (Table 17). Based on input from key informant interviews, it appears that this is due to similar factors as those noted in consumer focus groups: ongoing gaps, such as in meeting needs for rental assistance and low income housing, in which Ryan White funds are incapable of fulfilling consumer need, and developing gaps among emerging consumer sub-populations, such as immigrants and persons without legal status.

Only two categories experienced significant increases from 1999 to 2001 in the percent of providers who identified them as gaps: client advocacy and ambulatory medical care. Client advocacy ranked as the 11th highest gap in 1999, with 12% of providers identifying lack of access to one or more of the sub-components of this category (benefits counseling other than by a case manager, medical information about HIV/AIDS, interpreter services and peer or client advocacy). In 2001, client advocacy rose to the number four gap, with 28% of providers identifying a service gap in this category for the clients. The bulk of this increase is related to the addition of non-case management benefits counseling and peer advocacy to the overall service list on the survey, neither of which were include on the 1999 survey.

Table 17. Comparison Between 1999 and 2001 Provider-Identified Service Gaps

Service	1999 % (N=224)	2001 % (N=253)
Adult day health	10%	12%

Alternative/non-Western therapies	15%	14%
Ambulatory/outpatient medical care	2%	10%
Case management	9%	11%
Child care	8%	6%
Client advocacy	12%	28%
Counseling (emotional support)	23%	25%
Dental care	22%	27%
Direct emergency financial assistance	22%	18%
Drug prescription programs (ADAP)	8%	13%
Food/meals	7%	10%
Home health care	11%	14%
Housing assistance/related services	46%	44%
Insurance programs	16%	17%
Legal assistance	13%	13%
Mental health therapy/counseling	32%	30%
Referral	3%	3%
Substance use treatment/counseling	26%	32%
Transportation	19%	23%
Volunteer home chore	4%	9%

NOTE: The categories of "Health Education/Risk Reduction" (reported as a gap by 6% of providers in 2001) and "Treatment Adherence Support" (reported by 21% of providers in 2001) were not included on the 1999 provider survey. As a result, cross-year comparisons are not possible.

In addition, the percent of providers who noted that medical information about HIV/AIDS was lacking for their clients rose from 3% in 1999 to 9% in 2001. Based on interviews with key informants, this gap is primarily due to the increase in clients whose primary language is neither English nor Spanish, and for whom written materials about HIV are less readily available.

Although the increase in the percent of providers who noted a gap in their clients' access to primary care is significant, it remains relatively small (2% in 1999; 10% in 2001). Key informant interviews revealed that this gap is not actually due to lack of available slots for medical care. Rather, providers noted that the gap was seen as being related to increasing numbers of clients with mental illness and substance use histories (for whom these co-morbidities often serve as barriers to clients maintaining medical care) and the emerging population of refugee PLWH persons without legal standing. For these individuals, cultural norms against seeking medical care until one is very sick (or lack of trust in the Western medical system) was the key access barrier that prevented clients from obtaining the level of care their providers believed they needed.

Comparison between Consumer and Service Provider Gap Rankings: As in previous years, consumers and providers differed greatly in the service gaps they identified in the King County Continuum of Care. Significant differences emerged in the percentage of consumers and providers identifying gaps in almost two-thirds of the 22 Ryan White service categories, with providers being more likely than consumers to identify service gaps in all but two of those categories.

It is difficult to determine if this disparity represents actual differences in consumer versus provider perceptions of service gaps, or a methodological limitation (since consumers were asked to identify personal gaps while providers were asked to identify service gaps across the entire population of clients with whom they worked). Aggregate provider response may, in fact, over-state gaps by inflating gaps for small numbers of consumers into system-wide problems. Conversely, it is possible that provider responses were more reflective of actual gaps for populations that the consumer survey may have under-sampled: housing (homeless persons), mental health therapy (mentally ill persons), substance use treatment (chemically dependent persons) and transportation (PLWH living in non-urban parts of the county).

Similar to 1999, the largest disparities in consumer and provider-identified service gaps emerged in the areas of housing assistance, mental health counseling, and substance use treatment. Access to housing and housing-related services ranked first among provider-identified service gaps (44%), but ranked 5th as a consumer-identified gap (19%). Similarly wide disparities occurred in the areas of mental health counseling (identified as a gap by 30% of providers, but only by 10% of consumers) and substance use treatment (32% of providers, 4% of consumers). In addition, a significant gap emerged in 2001 between providers who identified transportation gaps for their clients (23%) versus consumers who noted this gap (3%).

Providers were also significantly more likely than consumers to identify gaps in the new category of treatment adherence support (21% versus 5%). Interestingly, of the 469 consumer survey respondents who reported taking at least one type of HIV-related medication (87% of total), 35% reported having difficulties taking the medications as prescribed. Thus, it appears that the majority of consumers who are experiencing treatment adherence problems do not believe that formal program support is lacking in assisting them with adherence.

H. Comparison of Service Priorities and Service Gaps

Consumer-identified service priorities as compared to service gaps: Comparing service gaps with service priorities helps determine the magnitude of potential system inadequacies and supports strategic planning and resource allocation decisions. Table 18 lists the top ten consumer-identified service priorities in comparison with the gap ranking and percentage for each service. Seven of the top ten consumer priorities also ranked among the top ten gaps.

Consistent with results from 1999, the services that consumers reported as having the highest priority-to-gap ratios were emergency financial assistance (31% of consumers rating the service

as a priority and 24% identifying it as a gap), alternative therapies (29% and 22%, respectively) and client advocacy services (35% and 20%, respectively).

Table 18. Service Priorities as Compared to Service Gaps from Consumer Surveys

Service	PRIORITY (n=511)		GAP (n=538)	
	Rank	% of Resp.	Rank	% of Resp.
Ambulatory/outpatient medical care	1	63%	21	1%
Dental care	**2**	**56%**	**6**	**15%**
Case management	3	50%	18	4%
Housing assistance/related services	**4**	**47%**	**5**	**19%**
Insurance programs	5	41%	13	6%
Drug prescription program (ADAP)	6	40%	17	5%
Client advocacy	**7**	**35%**	**4**	**20%**
Direct emergency financial	**8**	**31%**	**1**	**24%**
Alternative, non-Western therapies	**9**	**29%**	**2**	**22%**
Food/meals	**10 (tie)**	**29%**	**9**	**10%**
Mental health therapy/counseling	**10 (tie)**	**29%**	**8**	**10%**

Outpatient medical care and case management (identified among the top three service priorities across almost all sub-populations of PLWH) were rarely identified as gaps. Only 1% of consumers reported that they needed, but could not obtain outpatient medical care, and only 4% identified case management as a service gap.

I. Access Barriers

The survey asked all consumers who identified services as "need, but can't get" to provide specific reasons why they could not access the service. Responses were coded by type of barrier identified. Table 19 includes cumulative responses of consumer-identified access barriers across all service categories.

Table 19. Access Barriers from Client Surveys (N=538)

Rank	Barrier	Number of Respondents	%
1	Lack of information	140	26%
2	Financial (can't afford it)	97	18%
3	Not available/service doesn't exist	38	7%
4	Eligibility (based on financial status)	36	7%

5	Quality of service is unsatisfactory	34	6%
6	Geography (live too far away)	30	6%
7	Waiting list; not enough services	27	5%
8	Conflicts with schedule or work hours	24	5%
9	Haven't asked yet	21	4%
10	Eligibility (based on disability status)	20	4%
11	Eligibility (non-specific)	15	3%
12	Client is uncomfortable/afraid to ask	10	2%
13	Entitlement amount is too low	9	2%
14	Agency is unresponsive to request	6	1%
15 (tie)	Request for service is in process	5	1%
15 (tie)	Language barriers	5	1%
17 (tie)	Lack of comfort at agency/provider	3	1%
17 (tie)	Too much bureaucracy/paperwork	3	1%
19 (tie)	Eligibility (based on citizenship status)	2	<1%
19 (tie)	Concerns about confidentiality	2	<1%
21 (tie)	Discrimination based on sex, race, etc.	1	<1%
21 (tie)	Criminal history/violent behavior	1	<1%

The two main barriers identified by consumers in accessing services were lack of information about available services (identified as a barrier by 26% of respondents) and inability to afford services (reported by 18% of respondents). No other barriers were identified by more than 7% of consumer respondents. These results are almost identical to barriers reported in both 1997 and 1999, although the percentage of consumers who identified financial barriers to accessing services has decreased from 25% in 1999 to 18% in 2001.

Unlike previous years, no significant differences emerged in identifying access barriers based on disease status. In prior years, persons who were HIV+ and symptomatic were more likely to experience barriers to accessing services than either HIV+ asymptomatic consumers or persons living with AIDS. The magnitude of the differences has decreased in the past four years. HIV+ asymptomatic consumers remain somewhat more likely than other PLWH to report a lack of information about available services and problems affording needed services, most likely due to needs-based service criteria in some service categories that prioritize disabled individuals over other potential service users.

It bears noting that in most service categories, many of the consumers who identified access gaps failed to identify specific barriers that contributed to their lack of access. As a result, "no

answer" accounted for between 20%-50% of access barrier response, depending on the service category. This is largely due to the nature of the open-ended response option. As a result, it is possible that the actual percent of consumers who have experienced one or more of the barriers mentioned is larger than is quoted on Table 19.

Access barriers by specific services: In most service categories, no pattern emerged regarding specific access barriers, with consumers reporting a mix of different barriers. These included financial and geographic barriers, lack of information and others. In many cases, survey respondents did not provide any reasons why they could not access a needed service. In some service categories, however, a clearer picture emerged regarding the association between a specific type of barrier and gaps in service delivery. The areas which were identified as largest service gaps associated with specific access barriers are:

- Alternative/non-Western therapies: Financial barriers to accessing care emerged as the most frequent reason why consumers felt that they could not access alternative therapies. Forty-five percent (44 out of 97) of survey respondents who identified a gap in naturopathy noted this barrier, as did 42% of those who could not access acupuncture or Chinese medicine (34 out of 81). Lack of information, the main access barrier associated with gaps in this service in 1999, was only mentioned by 29% of PLWH who could not access naturopathy and 17% of those who had difficulty accessing acupuncture. Although insurance coverage for these therapies has improved somewhat in recent years, most insurance policies do not cover alternative therapies, and higher income consumers may not be eligible for Ryan White-funded services.

- Client advocacy: Within the component services in this category, lack of information about where and how to access the service emerged as the primary access gap. This barrier was identified by 42% of consumers (23 out of 55) who identified a gap in peer or client advocacy, 46% of those who identified a gap in access to medical information (13 out of 28) and 38% who noted a gap in non-case management benefits counseling (22 out of 58).

- Counseling (emotional support): Thirty-nine percent of the consumers who identified a gap in one-to-one peer emotional support (29 out of 74) identified lack of information as the main barrier. However, conflicts with scheduling and work hours was noted as the main barrier for consumers who wanted to access support groups (listed as a barrier by 21% who identified this gap [13 out of 63]). Geographic barriers (living too far from the where the service is offered) prevented 16% (13 out of 63) of those who needed support groups from accessing this service.

- Dental care: One third of the respondents who noted a gap in dental care services stated that they could not afford the service (27 out of 81; 54%), primarily because their insurance did not cover the procedures they needed. This represents a decrease in the percent of consumers who noted they could not afford dental care in 1999.

- Direct emergency financial assistance: Consumers who were unable to obtain financial assistance most commonly reported that they were unsure about where to access these funds.

This barrier was identified by 24% of consumers who could not get help paying for groceries (20 out of 85) and 30% of consumers who could not get help paying utility bills (30 out of 100). Approximately 14% of consumers who could not access each of the sub-components of emergency financial assistance stated they were above the income eligibility criteria for the programs.

- Housing assistance and related services: Lack of information also emerged as the main gap identified by consumers who could find help accessing low income housing (25%; 17 out of 67) or help paying rent (28%; 21 out of 75). Eligibility based on financial status was listed as the second largest barrier, reported by 12% of consumers in need of low income housing and 16% of consumers in need of help paying rent. In 1999, 20% percent of the consumers who reported needing, but not being able to access housing, noted barriers related to long waiting lists and limited housing options. In 2001, this concern was only identified by 9% of consumers who noted a gap in finding low income housing (6 out of 67).

- Mental health therapy and counseling: Of the 56 consumers who identified a gap in accessing professional mental health services, affordability and lack of information emerged as the two biggest access barriers. Each was identified as a barrier by 29% of PLWH unable to access mental health services (16 out of 56).

J. Access Services

In response to the Health Resource Service Administration's increased focus on medical care access and engagement, the Planning Council added a new component to the 2001 consumer and provider surveys. The 2001 survey asked consumers and providers to identify the services they felt were most important in helping them or their clients access or maintain medical care ("access services"). Table 20 includes cumulative consumer responses.

Table 20. Access Services from Consumer Surveys (N=500; 38 missing/invalid responses)

Rank	Service	Total Votes	%
1	Case management	290	58%
2	Insurance programs	238	48%
3	Dental care	228	46%
4	Client advocacy	216	43%
5 (tie)	Drug prescription program (ADAP)	202	40%
5 (tie)	Housing assistance/related services	202	40%
7	Counseling (emotional support)	148	30%
8	Mental health therapy/counseling	147	29%
9	Direct emergency financial assistance	130	26%
10	Alternative, non-Western therapies	127	25%
11	Food/meals	122	24%
12	Legal assistance	85	17%
13	Transportation	82	16%
14	Adult day health	61	12%
15	Referral	54	11%
16	Home health care	50	10%
17	Treatment adherence support	49	10%
18	Substance use treatment/counseling	43	9%
19	Volunteer home chore	33	7%
20	Health education/risk reduction	17	3%
21	Child care	13	3%

(NOTE: Because the purpose of this question was to inquire specifically about access to medical

care, the category of "primary medical care" was not included among the choices of access services in order to avoid redundancy. As a result, only 21 service categories are ranked, instead of the 22 noted in other sections of this report.)

In general, consumer rankings of access services were extremely similar to their rankings of service priorities. This may suggest that consumers believe the services that they feel are most important to them in living with HIV are also those that help them access and/or maintain medical care. However, several survey respondents noted in marginalia comments on the survey form that they were unclear about the distinction between "most important services" and "services that help you get or keep your medical care." As a result, similarities between consumer-identified service priorities and access services may be due to design flaws in the survey itself.

Only five of 21 service categories demonstrated significant difference in the percent of consumers who identified them as access services versus service priorities. Case management, ranked as a priority service by 50% of consumers, emerged as the highest ranked access service. Fifty-eight percent of respondents stated that case management was important in helping them get or maintain medical care. Consumers also were significantly more likely to identify client advocacy and insurance programs as access services than as service priorities. Dental care and housing assistance were the only two service categories identified by significantly fewer consumers as access services than as service priorities.

Table 21 lists the rankings of access services as defined by providers. As with consumer-identified rankings, provider rankings of access services tended to be very similar to their rankings of service priorities.

Several services emerged among providers as significantly higher access services than service priorities. Chief among these was client advocacy. Fifty-seven percent of providers ranked client advocacy as a key access services, versus 39% of providers who identified client advocacy as a service priority. Each of the component parts of the category (medical information, benefits counseling, interpreter services and peer or client advocacy) were ranked as an access service by higher percentages of providers than as a service priority.

Insurance programs and transportation services were also significantly more likely to be identified by providers as services that helped consumers access or maintain their medical care. Thirty-three percent of providers listed transportation services as a key access service, up from 23% of providers who listed it as a service priority. Thirty-two percent of providers listed insurance programs as a key access service, up from 23% of providers who listed it as a service priority.

Several services were significantly less likely to be seen as key access services than as general service priorities by providers. These include drug prescription programs (listed as a service priority by 55% of providers, but as an access service by only 42%), dental care (22% versus 9%) and food/meals (12% versus 3%). It may be that providers did not consider drug prescription programs as a service that helped consumers access medical care because this service could be

viewed as an outcome of medical care itself.

Table 21. Access Services from Provider Surveys (N=245; 11 missing/invalid responses)

Rank	Service	Total Votes	%
1	Case management	169	69%
2	Client advocacy	139	57%
3	Mental health therapy/counseling	137	56%
4	Substance use treatment/counseling	128	52%
5	Drug prescription programs (ADAP)	103	42%
6	Housing assistance/related services	88	36%
7	Transportation	82	33%
8	Insurance programs	79	32%
9	Treatment adherence support	74	30%
10	Counseling (emotional support)	67	27%
11	Adult day health	49	20%
12	Home health care	32	13%
13	Referral	31	13%
14 (tie)	Alternative, non-Western therapies	22	9%
14 (tie)	Dental care	22	9%
16	Legal assistance	15	6%
17	Direct emergency financial assistance	14	6%
18	Health education/risk reduction	11	4%
19 (tie)	Child care	8	3%
19 (tie)	Food/meals	8	3%
21	Volunteer home chore	7	3

K. Estimates of Unmet Need

Estimates of overall unmet service needs can prove very useful in making funding allocations and planning service delivery. In order to estimate how many consumers might have an unmet need in each of the services in the Continuum of Care, data from the consumer survey were compared to current epidemiological data. "Unmet need" data was drawn from consumer survey respondents who identified a service as "need, but can't get." Overall unmet need figures were derived by applying survey response percentages across estimates of King County male and female PLWH, controlling for known HIV status. Table 22 shows the estimated consumer need in each service category, and includes breakdowns by component services in collapsed categories (shown in italics).

Because survey sampling was devised in efforts to reach traditionally under-represented populations, need estimates were adjusted to better approximate the percentages of male and female PLWH and PLWA in King County. Survey response included purposeful over-sampling of women (14% of survey respondents versus an estimated 9% of PLWH) and persons who were living with AIDS (53% of survey respondents versus 33%-49% of all PLWH, depending on whether the high, low or midpoint estimated number of PLWH in the county is used). To derive more accurate estimates of need, the percentage of respondents in need within each service category was applied to the estimated number of male and female PLWH who were aware of their HIV+ status and male and female PLWA in the county. Gender and level of illness-specific figures were then added to develop an aggregate projection of need in each service category.

Service need estimates were calculated as follows:

1) Use of local epidemiological data: Asymptomatic HIV infection has only been reportable in Washington State since September 1999. Seroprevalence estimates for the county were taken from Public Health's Epidemiology Program publication, HIV/AIDS Epidemiology Profile for Community Planning. Based on these data, the Epidemiology Program estimates that 6,000 - 9,000 persons in King County are believed to be infected with HIV, with 7,500 considered the midpoint value.

2) Breakdown of seroprevalence data into gender and level of illness: Public Health's HIV/AIDS Epidemiology Program maintains current surveillance data regarding cumulative AIDS case counts and deaths in King County. As of 6/30/01, the number of persons presumed living with AIDS in the county was 2,643. If we assume that AIDS case reporting is approximately 90% complete, this would suggest a total of approximately 2,940 persons living with AIDS in King County. This includes approximately 2,725 males and 215 females.

The number of males living with AIDS in need of each of the various services was estimated by applying the percentage of male PLWA who stated they used or needed, but could not get, each service to the overall figure of male PLWA in the County. The same formula was used to derive the estimates for female PLWA in need.

3) Estimates of persons living with HIV (non-AIDS) in King County: The number of persons living with HIV (non-AIDS) in King County was derived by subtracting the estimated number of persons living with AIDS in the county from the total HIV+ estimate:

Low estimate:	6,000 - 2,940 = 3,060
Midpoint	7,500 - 2,940 = 4,560
High estimate	9,000 - 2,940 = 6,060

According to seroprevalence studies conducted in King County, the Epidemiology Program estimates that approximately 91% of the total number of persons living with HIV in King County are male and 9% are female. These percentages were multiplied across the total seroprevalence estimates for the County to derive the following numbers:

Males living with HIV (non-AIDS):

Low estimate:	3,060 x .91 = 2,785
Midpoint	4,560 x .91 = 4,150
High estimate	6,060 x .91 = 5,515

Females living with HIV (non-AIDS):

Low estimate:	3,060 x .09 = 275
Midpoint	4,560 x .09 = 410
High estimate	6,060 x .09 = 545

3) Estimate of HIV+ persons who are aware of their serostatus: Based on estimates from the Centers for Disease Control (CDC), approximately 75% of the estimated 900,000 HIV-positive persons in the United States know they are infected. Obviously, people who are living with HIV would not become consumers of HIV-related services until they are actually aware of their serostatus. In order to derive a more accurate estimate of consumers in need of services, it is therefore necessary to limit projections for HIV+, non-AIDS consumers to those individuals aware of their infection. As a result, the figures derived above for males and females living with HIV (non-AIDS) were multiplied by .75 to derive estimates of King County PLWH who are potential consumers of HIV-related services.

Males living with HIV (non-AIDS) who are aware of their serostatus:

Low estimate:	2,785 x .75 = 2,089
Midpoint	4,150 x .75 = 3,113
High estimate	5,515 x .75 = 4,136

Females living with HIV (non-AIDS) who are aware of their serostatus:

Low estimate:	275 x .75 = 206
Midpoint	410 x .75 = 308
High estimate	545 x .75 = 409

The number of males living with HIV (non-AIDS) in need of each of the various services was estimated by applying the percentage of males living with HIV (non-AIDS) who stated they used or needed, but could not get, each service to the low, midpoint and high estimates of males living

with HIV (non-AIDS) in the county. The same formula was used to derive the estimates for females living with HIV (non-AIDS) in need.

4) Calculation of percentage of consumers in need by service category: The need estimates for male PLWH, female PLWH, males living with AIDS and females living with AIDS were added to derive an overall estimate of consumer need in King County.

Table 22. Estimates of Unmet Consumer Needs by Service Category - King County

Service Category	Unmet Need		
	Low Estimate[1]	Midpoint[2]	High Estimate[3]
Adult day health	239	292	346
Alternative/non-Western therapies	1,176	1,453	1,729
Acupuncture/Chinese medicine	*785*	*957*	*1,128*
Naturopathy, herbal medicine	*942*	*1,148*	*1,355*
Ambulatory medical care	47	69	91
Case management	205	262	319
Child care	48	53	59
Client advocacy	1,010	1,251	1,493
Benefits counseling (other than CM)	*536*	*665*	*794*
Medical info about HIV/AIDS, tx., etc.	*274*	*354*	*435*
Interpreter services	*48*	*63*	*78*
Peer or client advocacy	*535*	*656*	*777*
Counseling (emotional support)	1,063	1,293	1,523
Support groups	*608*	*742*	*876*
One-on-one peer support	*740*	*912*	*1,083*
Spiritual and religious counseling	*361*	*450*	*538*
Dental care	794	988	1,182
Direct emergency financial assistance	1,224	1,457	1,690
Help paying utility bills	*943*	*1,142*	*1,342*
Help paying for groceries	*776*	*932*	*1,087*

Table 22 (Continued)

Service Category	Consumers in Need		
	Low Estimate[1]	Midpoint[2]	High Estimate[3]
Drug prescription programs	243	305	367
Food/meals	472	593	714
Home delivered meals	*222*	*285*	*348*
Food bank/receiving free groceries	*296*	*368*	*440*
Health education/risk reduction	128	162	196
Home health care	251	290	328
Home care worker (paid attendant)	*148*	*172*	*195*
Home nursing or infusion care	*144*	*167*	*191*
Skilled nursing facility	*96*	*127*	*158*
Housing assistance	987	1,277	1,567
Help finding low income housing	*649*	*852*	*1,054*
Help paying rent	*723*	*921*	*1,118*
Insurance programs	312	404	496
Legal assistance	553	670	787
Mental health therapy/counseling	534	675	815
Referral	459	556	653
Substance use treatment/counseling	208	271	335
Harm reduction	*124*	*156*	*188*
Help quitting drug/alcohol use	*144*	*191*	*239*
Transportation	160	193	226
Treatment adherence support	245	303	362
Volunteer home chore	366	422	479

(1) Assuming 6,000 PLWH in King County
(2) Assuming 7,500 PLWH in King County
(3) Assuming 9,000 PLWH in King County